

Local authorities' use of Independent Living money

When the original Independent Living Fund (ILF) closed, the Government made additional money available to local authorities with their transitional community care grants. The Disablement Income Group has conducted a UK-wide investigation of how that additional money has been used and what changes in disability policies and practices it has promoted. Ann Kestenbaum who carried out the research found that:

- f** There was a lack of clarity about the purpose of the Independent Living Transfer which has impaired effective use of the money.
- f** The money has been used for variously defined client groups. In some authorities it has had a significant impact on provision for disabled people; in others it has had no specific impact at all.
- f** Several authorities have used the money to try to continue the spirit of the old ILF by setting up indirect payments schemes, using third-party organisations to support user-managed care.
- f** Apart from the involvement of organisations of disabled people in indirect payment schemes, there was little consultation with disabled people about use of the money.
- f** The provision of £200 per week of services for applicants to the Independent Living 93 Fund has enabled some disabled people to get cash top-ups from that Fund. But there have been significant obstacles and the number of successful applications has been low.
- f** With growing financial pressures because of the residential care needs of elderly people, many SSD managers believe that a ring-fence for the Independent Living Transfer is essential if the currently low priority given to younger disabled people is to be raised.
- f** There is apprehension about what happens after 1995/96 when the Independent Living Transfer is no longer separately identified in the Revenue Support Grant.

Background

From April 1988 to March 1993 the Government-funded Independent Living Fund (ILF) made cash awards to more than 23,000 disabled people. These regular payments enabled them to continue to live in their own homes and get practical help with everyday personal and domestic tasks when and how they required it.

Early in 1992 the Government acknowledged the success and popularity of the ILF, and announced that a successor, the ILF Extension Fund, would continue to administer existing awards. It later announced that the ILF 93 Fund would also be set up to make *new* awards, though with much more restrictive eligibility criteria than the old ILF.

With the Government's statement about the 93 Fund came the news that local authorities would be provided with some additional money. An element of the transitional community care transfer would be separately identified as "related to the closure of the Independent Living Fund and the different basis on which the new arrangements for disabled people would operate". For the purposes of this research this additional money is referred to as the Independent Living Transfer, or ILT.

Compared with the overall community care transfer, the ILT is small. In England, for example, the 1994/95 allocation is £64.1 million compared with £735.9 million. But its importance lies in its unique potential for raising the profile of Independent Living and for promoting more appropriate SSD policies and services for disabled people.

	1993/4 (£m)	1994/5 (£m)	1995/6 (£m)
England	26.8	64.1	99.9
Wales	1.6	3.9	6.0
Scotland	2.8	6.8	10.6
Northern Ireland	1.0	2.4	3.7
Total ILT	32.2	77.2	120.2

The ILT will be separately identified for only three years. After this any related Government funding will be included in the revenue support grant.

DIG's research during 1994 aimed to draw attention to the existence of the ILT; to investigate how it was being used; to identify whether it had promoted any change in planning or service delivery for disabled people; and to point up the potential for using this money in ways that will promote Independent Living.

Monitoring the ILT

The first year of the ILT was unique because it was also the first year of full community care implementation and brought major changes in the way social services and social work departments operated. Demand was unpredictable and many information systems lacked the sophistication to track expenditure in detail.

The Government did not require local authorities to monitor the ILT. Although two-thirds of them chose to identify a separate ILT budget, quantitative breakdowns of expenditure by client group and service were generally only available in very rough terms. An overview of how the ILT was treated, rather than a detailed picture of how all the money was eventually spent, was the outcome of DIG's investigation into the use of the 1993/94 allocation.

Lack of clarity about purpose

There was a lack of clarity about the purpose of the ILT which delayed planning for the most effective use of the 1993/94 allocation.

The Government had provided some preliminary information about the new 93 Fund, but no other guidance about the ILT. It took some time for many authorities to appreciate the lack of restriction on how the money might be used and this uncertainty delayed the formulation of firm policy.

Where it was budgeted, the ILT was often treated as contingency money. In particular, demand related to potential applicants to the ILF 93 Fund was a significant unknown and there was a great deal of uncertainty about the mechanics of making successful applications to that Fund. Confusion about eligibility criteria and ways of costing the local authority input to jointly funded care packages presented major problems during the first six months of the 93 Fund's operation.

The delay in policy-making also meant that care management training often did not adequately cover the complex care arrangements involved when severely disabled people want to live independently.

Impact on disability policies

Because it was a small proportion of the transfer funds, the importance of the ILT was overshadowed by the other major community care changes that came into effect in April 1993. These mainly concerned policies for elderly people, so the potential for using the ILT to raise social services priorities for disabled people was often diminished and sometimes lost. This was regretted by many of the social services managers who contributed to the research.

In many authorities, either the 1993/94 ILT was underspent, or it was vired for other uses before the end of the year, or it was offset against overspent budgets in the end-of-year accounts, or a combination of these. Because there was no Government requirement that the ILT be tracked, it was often spent in an ad hoc way with the result that it had a minimal impact on policies for disabled people. In some authorities managers felt that there had been no impact at all.

By contrast, however, there were other authorities where the ILT was felt to have had an important impact because its very existence had focused attention on a low priority client group.

Overall, where the ILT did have a practical impact, it did so in one or more of four ways:

- developing more flexible in-house services;
- developing and purchasing independent sector provision that would extend choice or provide services that the authority could not directly provide itself (e.g. night care);
- supplementing individual packages of care for people with complex needs to allow more expensive community care provision as an alternative to institutional care;
- establishing and supporting personal assistance schemes to offer disabled people choice and control in their care arrangements.

Personal assistance schemes

Some authorities have deliberately used the ILT to continue the spirit of the old ILF by developing and supporting indirect payment personal assistance schemes. The full research report describes the approach to third party arrangements, eligibility criteria and support services in seven of these schemes.

The survey revealed widespread SSD interest in using third party organisations (of disabled people when feasible) to support user-managed care, but in general there was very little consultation with disabled people about overall use of the ILT.

The beneficiaries

The ring-fenced policies of social services departments revealed various approaches to choosing the client groups to benefit from the ILT. The eligibility criteria of the ILF 93 Fund were initially often the basis for this choice (although criteria were often widened later).

Beneficiaries would have to be aged 16-65 and have a disability severe enough to qualify them for the higher rate of Disability Living Allowance (DLA). The ILT was sometimes added to the physical disability budget, sometimes split between that and that for learning disability, and sometimes left flexible within the age range (especially where there was less specialisation within SSDs).

Two factors have a significant effect on how the ILT has been used for different client groups. One is about the concept of Independent Living, and whether user control or simply keeping people out of residential care is the key issue. At one extreme, funding can be restricted to those who have the drive and ability to manage their own care. At the other, it can provide traditional domiciliary care services which enable an individual to live at home but have little real control beyond that. The former approach tends to direct the resource towards younger physically disabled people who are considered capable of self-managing.

A related issue is the question of whether the ILT is the right money to use for supporting terminally ill people in the community. The exclusion by the 93 Fund of people with short life expectancy, and therefore with short-term needs, has raised the profile of that question.

The second important factor relates to the size of specialist budgets and the demands upon them. If long-stay hospitals are closing, the ILT is likely to be used for people with learning disabilities who have to be resettled in the community. If the local prevalence of AIDS is high, then the ILT may be used to offset the pressure on that budget. The main demand for resources, however, continues to be driven by the growth in support needs of the elderly.

Financial pressures

It is increasingly difficult to use ILT money that is not separately ring-fenced for anything other than the ad hoc support of other budgets.

The research also showed a growing tendency to use available money for one-off or short-term projects. This reflects the uncertainty about SSD capacity for funding on-going commitments such as community care packages.

In the first year of the transfer, the ILT was widely used for equipment and adaptations. It supported budgets that were under great pressure (partly as a result of more restrictive Government policies relating to the Disabled Facilities Grants and subsidies for adaptations), but the unmet need in this area also provided SSDs with a practical way of quickly mopping up an anticipated ILT underspend.

Ring-fencing the money

Some authorities which chose not to ring-fence the ILT but to devolve it out to general care management budgets are satisfied with the greater flexibility achieved in the provision of appropriate and requested care across the board. But most ring-fenced the money in some way, only amending or abandoning that protection in the face of an underspend. The research found that many SSD managers feel that it is important to ring-fence this money for disabled people. This view might well be expected from those with specialist responsibility for disability, but it is shared by many other senior managers including those with overall responsibilities for planning adult services. Having a separate budget is seen as a way both of preserving some of the legacy of the old ILF, and of raising, monitoring and maintaining the priority for clients who have had a low priority in the past.

Severely disabled people often need quite complex packages of care. It is less likely that their needs will be fully assessed if there is no dedicated budget to back such assessments. This is especially so where their needs are not just for basic and essential care, but for enabling care which promotes their independence from institutions or family. Provision which is just a bolt-on to services essentially designed for elderly people is increasingly seen to be inappropriate.

Apprehension about 1996/67

For the first year there was a widespread lack of knowledge about the existence of the ILT; there is now apprehension about what happens after 1995/96.

Unlike the rest of the community care transfer, one year's ILT is not taken into the baseline grant for the next but accumulates. After the third year a UK ILT of £120 million suddenly disappears as a separate item unless local authorities decide individually to identify and ring-fence the money from their baseline budgets. A possible fourth year of the community care transitional transfer is currently being discussed, but it is as yet unknown how this will be allocated.

About the study

The investigation covered the whole of the UK and was supported by the Association of Directors of Social Services and the Association of Directors of Social Work. Questionnaires to Directors in England, Wales and Northern Ireland identified which authorities had marked out separate budgets for their 1993/94 ILT. Follow-up work provided more detail about policies and expenditure. Face-to-face interviews with SSD managers in six English counties, one Welsh county, three metropolitan boroughs, two London boroughs and one Northern Ireland board were supplemented by telephone interviews with managers in a wide range of other authorities, including seven in Scotland. In addition, the research involved visits to seven authorities (five English, two Scottish) where the ILT had been used to support indirect payment personal assistance schemes.

Further information

An Opportunity Lost? Social services use of the Independent Living Transfer by Ann Kestenbaum is published by The Disablement Income Group (£8 incl p & p).

For the report or further information contact: DIG, Unit 5, Archway Business Centre, 19-23 Wedmore Street, London N19 4RZ. Tel: 071 263 3981.

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- 19 Counselling for people disabled through injury (Apr 92)
- 26 The experience of young people with arthritis (Sept 92)
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Published by the
Joseph Rowntree Foundation
The Homestead, 40 Water End
York YO3 6LP
Tel: 01904 629241 Fax: 01904 620072
ISSN 0958-3815

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